

APPENDIX B

January 13 1994

JRB ASSOCIATES JACKSON
LONGITUDINAL STUDY

INTERVIEWER S GUIDE

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In this document and in the survey instrument members of the *Jackson* Class are referred to in a number of ways as the individual, the mover, the client, and finally the resident. Because we will primarily be interviewing and observing them in their residential settings, the preferred generic term (for the indefinite future) will be resident.

PRE-INTERVIEW STEPS

Residents vary widely in their cognitive ability and in their expressive communication. An individual may also exhibit a different level of attention, energy, and ability to communicate from one interview situation to the next. In setting up the interview/observation visit, it will be helpful to consult with staff about the best time to visit a resident from the point of view of gaining maximum participation by the resident himself or herself. If a proxy is to be present to speak for the resident to a greater or lesser degree, that person should be the staff member closest to the resident, and the interview date and time should be arranged so that she or he will be present. (See *Helper/Proxy* below.)

Consent

To the extent possible, the interviewer should introduce himself/herself to the resident and make the resident aware of the purpose of the JLS, the interview process, affording her/him an opportunity to choose whether to participate. This is the purpose of the consent form on the cover sheet. It does not have to be read exactly as written so long as its intent is clear.

Survey

The pretest (T_0) is being administered in the institutions to a stratified sample of 60 individuals during Years 1 and 2 to establish baseline data. Beyond that, every *Jackson* resident who moves into a New Mexico community will receive a visit each year during the five years of the study. To keep track of our data, it is important to identify which visit you are making to a given client. During Year 2, this could be T or T₁. Depending on when all the original *Jackson* clients complete moving, the project may be making T₁ and T₂ visits in future years as well.

Residence

When the interview is held at the resident's home in the community (rather than at Los Lunas or Fort Stanton), we want to try to characterize the resident's living arrangement for possible cross-correlations at a later stage of the study. The resident's address is a practical piece of information we simply need to keep current. The residence type is usually an apartment or house which may be shared by two or more individuals with developmental disabilities and staff. This is usually termed a 'supported living arrangement' rather than a 'group home' unless it begins to take on an 'institutional' character in which residents are treated as a group rather than individuals. (If staff call it a group home, it probably is!)

Indicate the ratio of staff to residents (eg 1/2 - this means 1 staff member on duty at a given time for each 2 residents) and how many hours of each day staff are present (24 hours means staff are present all the time including transport time to and from the residents' daytime activities and overnight). If overnight staff are required to be awake, so indicate.

Helper/Proxy

In the institutions each of the residents was assigned a "helper," who was the staff person closest to the individual, or the person the individual most trusted or confided in. A unique feature of the JLS research design is the use of this person as a proxy or surrogate who can "speak for" the resident in situations where the interviewer is unable to obtain the information directly from the resident. This procedure enables us to include in this study individuals with little or no expressive communication who have typically been ignored in other studies of the effects of deinstitutionalization.

The movement of the resident into a new situation means that the "helper" typically is no longer available to him/her (or to us in conducting this study), and that fact may, in itself, affect the resident's quality of life. New relationships, however, are possibly being established over time, and it may be of interest to know whether the resident's helper (i.e., that staff person closest to the resident) remains the same person or changes during the course of the study. We therefore want to know the helper's name and the length of time she or he has known or worked with the client.

APPROACH TO SPECIFIC INTERVIEW QUESTIONS

Q1 Do you like living here? A LOT SOME NOT MUCH DK/NA

In asking this question (and others like it) it may be helpful to use a visual cue to help the resident discriminate between the answer categories. As an example: "a lot" would be arms held out wide; "some" would be arms open to the width of shoulders, and "not much" would be hands held a few inches apart.

If you sense the resident is answering based on the last category presented, you should change the order of presentation; e.g., "some...not much...a lot...". This technique will apply to all questions in which you feel you are getting an echolalic response. (If this occurs and you are unable to be reasonably sure that you know what the resident means — and the proxy is unable to clarify the resident's intent - mark DK/NA and note the problem on the instrument.)

1.1 What do you like about it?

1.2 What don't you like about it?

In probing for a response to 1.1, rephrasing may include: "What's good about it?" "What makes you feel good?" "What's fun?" For 1.2, "What's not good about living here?" "What doesn't feel good?"

Q2 Have you lived somewhere else before? YES NO

Q2.1 If yes, how did you like living there?

A lot

Some

Not much

DK/NA

This question may elicit more than one place where the resident has lived before. Focus primarily on the *last* place the resident lived before moving here. Note on the form whether the resident has a different response to other remembered locations. Don't be concerned about the order.

Q3 If you could live anywhere you want, where would you live?

3.1 What would be better about living there?

3.2 What might not be so good about it?

This question and its tree'd follow-up allow the resident, if he or she is able, to express a variety of possibilities. This may be hard for some to do. They may be perfectly happy where they are, or unable to imagine anything different. In probing, ask, "Who would you want to live with?" "What kind of place would you like to live in?" 3.1 and 3.2 are not applicable unless the resident is able to express a preference for something different from his/her current situation.

Q4 How comfortable are you with your current home?

| Satisfied

| Somewhat satisfied

| Dissatisfied

Why?

This question, coming after the resident has had a chance to think about other possibilities, restates the intent of Q1. Again, visual gestures may be helpful, and changing the response order may be indicated if echolalia is likely.

Q5 Who do you like?

This begins a series of questions about the resident's relationship to the staff or people in charge.

Q5.1 Do you like the people here who are supposed to help you? ALL OF THEM MOST OF THEM NONE OF THEM DK/NA

It may be necessary to obtain the names of the people who work in the home and ask the resident about each of them. However if the resident or helper quickly answers "All of them" or "None of them." probe by asking "Is there anyone here you don't [do] get along with (or who understands you)?"

5.2 Tell me what you like about them. Do they check all that apply and note additional reasons mentioned.J
| **listen to you?**
? **make you feel happy?**
? **understand what you need?**
? **What else?**

Try to elicit a response *before* you list the options indicated on the survey form.

5.3 Does anyone here hurt you? YES NO DK/NA
? **[If yes] Who is that? [Find out if staff or peer.]**
? **[If yes] What do they do to hurt you?**
? **Is there JUST ONE | A FEW | LOTS of people who make you feel this way?**

It is often difficult to ask these questions, depending on the interview context and the relationship you have been able to establish with the resident and staff present. It may be helpful to preface the initial question with a statement like "Now here is an important question I'd like you to think about..." and to explain that "hurt" is not just physical, but something that "makes you feel bad." We want to find out whether the perceived "hurt" comes from staff or peers. You can ask, "Well, how about [roommate, friends]? Do any of them hurt you?" When asking "Who is that?" just ask for a first name. (Remember, we are not monitors! We are not attempting to investigate or report on anyone!)

When establishing how the individual is hurt, also probe for how often this happens.

Q6 Do you have a special friend here?
| I DO | MAYBE | I DON'T

6-1 [If yes] Who is that? [Find out if staff or peer.] Here, we are also interested in whether the person is viewed as an intimate "boyfriend" or "girlfriend." **Q7 What do you like to do with your friends?**
[Record activities; number of discrete activities.]

Use the names of friends given in 6.2 if needed to elicit specific activities. (What do you like to do with [friend]?)

Q8 Do friends visit you? YES NO

Staff who are friends are not considered as visiting friends when they come to work!

Q11 - 13 Are you: | USUALLY | SOMETIMES | NOT (seldom or never)

**happy?
sad?
afraid?
angry?**

Begin this section with an introduction such as "I'm going to ask you some questions about your feelings - happy sad afraid angry. So how do you usually feel?" If the person chooses one feeling as usually, record that and probe for the others. (For instance, if the person answers "happy" as her usual feeling, ask "Do you ever feel sad?" Etc.)

Q15 I guess you get out of bed in the morning every day. Is that right? [Not coded; lead in to following]

15.1 Who picks what time you get up in the morning?

- ? I do
- ? I do with staff or someone else's help
- ? Staff or someone else does

If the resident's response to these questions is not informative, a possible follow-up to get a fuller picture might be: "What if you don't want to get up some morning — What happens?"

15.4 Can you decide not to do some things if you don't want to?

- ? Yes I can
- ? Yes I can with staff or someone else's help
- ? No I can't

Again, a possible follow-up might be: "What happens if you don't want to go on [a planned activity]?"

Q19 Who picks the clothes you wear?

This may be too abstract. Probe: "When you get up in the morning, who chooses what clothes you wear?"

21.1 Do you keep your own money? YES NO

Code: Yes, if the individual keeps even a limited amount of her/his own money.

GENERAL

Hearing impaired residents

If an interpreter is used, questions involving time and other abstract concepts may be altered by the interpreter. Make sure you know how the interpreter is changing the question so that we get a valid response.

Helper responses

When a proxy answers a question, he or she may forget to try to speak for the resident (to answer as they believe the resident would) and the answers may be overbroad or employ jargon from the developmental disabilities field such as "He/she likes to do table tasks." The interviewer should remind the proxy to try to get into the resident's head and answer the question concretely as the proxy thinks the resident would answer it.

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